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Developmental Disabilities Special Investigative Committee
May 07, 2009

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The Developmental Disabilities Special Investigative Committee met at 12:30 p.m. on Thursday, May 7, 2009, in Room 1524 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing regarding Beatrice State Developmental Center. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Tim Gay; and Norm Wallman. Senators absent: Arnie Stuthman.

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SENATOR LATHROP: Okay. Well, I think we'll start. We're going to...we have a meeting today of the LR11 Committee, also known as the BSDC Committee and the purpose of that committee today. We've been meeting periodically and the purpose is to get updates and kind of try to find out what's going on in relationship to improvements in the state's provision of services to the developmental disability community. Maybe I'll introduce my colleagues and then we'll introduce you, have you give us a little background and kind of go there. My name is Steve Lathrop. I'm the Chair of the committee and I represent District 12. I'm joined by Senator John Harms from Scottsbluff, Tim Gay from Papillion, and Norm Wallman from Cortland, and my committee clerk is Chris Chapek, and my legislative aide is Doug Koebernick. Today we have in the past generally visited with Mr. Wyvill and we thought we'd spend the time talking to you, Mr. Dufresne, and perhaps we can begin by having you introduce yourself and give us a little information, kind of professional background, if you would. []

DERRICK DUFRESNE: I'll be glad to. First of all, thanks very much for the opportunity to be here. I can tell you that seven weeks ago I honestly didn't think I would be offered the opportunity that I have to spend time in the wonderful state of Nebraska. In January of this year, I started by 35th year of work in the field. I started working in a state institution in Virginia in 1974 with individuals with significant challenging, violent and aggressive behaviors; did that for five years. I then worked for a county in Virginia for three years where I ran a community residence program where we did respite, where

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we did supports for individuals with challenging behaviors. And then moved to Wisconsin in the early eighties and ran the largest nonprofit, at that point in the county, that did just services that were residential, didn't include vocational, transportation, whatever. And during the time that we were there in Wisconsin, we developed a reputation as a provider at that point of serving people in the community that basically either no one else was interested in serving or for whom there was not significant supports available to serve people. And then in 1989 my family and I moved from Madison, Wisconsin, to St. Louis where I went to school the first time. It took me some time to get through college so this was actually the second or third iteration, I guess, and ended up moving back to St. Louis and I've been in St. Louis since '89. I have a consulting business called Community Resource and over the last 20 years I have traveled to 49 of the 50 states providing consultation and training around issues related to disability and particularly individuals that require, I guess you'd say, specialized support. And so that's kind of...I mean I could obviously go on, Senator Lathrop, but that I guess gives you a little bit of a flavor. []

SENATOR LATHROP: Why don't you tell us when you were engaged by the state of Nebraska and what the scope of your purpose is here. []

DERRICK DUFRESNE: Sure. Sure. As I've kind of jokingly said, I was actually sitting in my office, which is my basement, minding my own business and I got a call from a colleague of mine that I've known for a long time that had been coming here a little while to work on what's called your money follows the person, and he asked me if I might be interested in coming to Nebraska to assist with some of the folks that were in the hospitals for whom there were some specialized support needs that were not readily available in the community. And I only knew enough to make me dangerous, which is probably still the case, about all of the ins and outs of this, but he mentioned that there were some opportunities here that I might be interested in. As I've kind of said to some folks, it probably is maybe a sickness but I kind of thrive on chaos and so the opportunity to come into a situation that required some supports was actually somewhat

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attractive to me. So how I got here was I then had a telephone conference with Tricia Mason and with Jodi Fenner and asked whether or not I would be interested in assisting for some of the people in the hospitals, to look and see whether or not for people for whom there was not yet something identified. And I've been making this clear all along that I feel like I've been engaged for something very specific and I'm not interested in going where I'm either not wanted, where it's not blessed for me to go or it's not seen as being necessary. So what I've said to the providers, what I've said to the service coordinators and what I've said to the parents is if something is already in place for people, I'm not here to be a look behind, I'm not here to be quality assurance for that. I'm here to work, when I'm asked, with individuals and families that are interested in transition into the community, so that was the original intent. []

SENATOR LATHROP: So the purpose is to help people transition into the community. Is it limited to just the folks that were designated as medically fragile and then moved out of BSDC into the hospital settings? []

DERRICK DUFRESNE: That's a great question and I can answer you as of today, because what keeps happening...and, by the way, I appreciate this and I'm not put off by it, but we keep finding intersecting points where it turns out that there may be the opportunity for some additional things. When I came in and started working with individuals and then, having known some of the providers in this state, started hearing about some of the limitations as we were meeting with providers that have caused some challenges, I won't say rejection but some challenges in terms of serving people in the community, I started asking what do your regulations permit. And Tricia said that she'd be happy to e-mail me these and I thought when somebody says they're going to e-mail you that this might be like 3-4 pages, and I got 126 pages worth of stuff that basically killed my printer, and looked and printed all of them off and read the regulations, and in the regulations were also the comments that have been made about the rewrite of the regulations, I guess, that you all have been underway for some time. And my comment about those regulations was not so much what was in them but what was missing,

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because I kept reading things about residences of four or more, but I didn't see specific residences for three or fewer. And I've been around long enough, and this is one of the things, frankly, that propels me, I've been around long enough and started in the field in the early seventies, when ENCOR was seen as Mecca and Nebraska was leading this country in terms of services and supports to people with disabilities, so I came with very high expectations because of the quality of services that were here. And so what I have been asked to do is to provide some recommendations about how those regulations might be looked at to try to keep the intent, first and foremost, of health and safety, which is critical wherever people live, but then offer the opportunity for a more flexible approach that has been come to be known around the country as supported living. And that supported living doesn't look at the diagnosis of the person and it isn't a readiness concept and it isn't built on the concept that you go from facility to facility but rather that you find a home for somebody. And I found it very interesting that of the 5,000 to 6,000, please don't quote me exactly, number of people that are living in the state supported by government services, that about 70 percent of them are living in settings already of less...of three or fewer people, so you already have numbers of people that are living in small settings. So I was asked anyway to provide some recommendations. []

SENATOR LATHROP: That would include living at home with Mom and Dad? []

DERRICK DUFRESNE: That gets supports. []

SENATOR LATHROP: Right. []

DERRICK DUFRESNE: But it's mostly people living in what you call I think either centers for the CDDs or other types of group settings. []

SENATOR LATHROP: I want to...I think you might have got a little astray on the question that I asked,... []

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DERRICK DUFRESNE: Okay. []

SENATOR LATHROP: ...which was...and I appreciate the information. You're working on the regulations with... []

DERRICK DUFRESNE: Yes. []

SENATOR LATHROP: ...the folks at Health. And the question I had was whether or not you were engaged to help find placement for just the people that were moved... []

DERRICK DUFRESNE: Right. []

SENATOR LATHROP: ...out of BSDC, or does your engagement include transitioning people from BSDC into a different setting? []

DERRICK DUFRESNE: Yeah. And actually, I did know that and I was...I guess I had a line drawn in my mind, Senator, and I'm sorry I didn't come back to it quickly enough. []

SENATOR LATHROP: That's all right. []

DERRICK DUFRESNE: Then we started talking about the fact that there are some individuals at BSDC that have been identified for...that may have the possibility of community placement for which there is not guardian opposition, and I was asked whether or not I would be willing to spend some time, as directed by the division, to look at some of those folks as well. And so that really hasn't started yet but, yes, I've been asked if I would. []

SENATOR LATHROP: Okay. So is it...you've specifically been engaged to help move folks from the hospital settings into a different placement. []

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DERRICK DUFRESNE: Yes, sir. []

SENATOR LATHROP: And that's grown into moving some of the people at BSDC, for whom there is not guardian opposition,... []

DERRICK DUFRESNE: Yes. []

SENATOR LATHROP: ...into a suitable community placement. And the third thing then would be working on our regulations. []

DERRICK DUFRESNE: Yes. []

SENATOR LATHROP: That's pretty much the scope of your contract with the state of Nebraska. []

DERRICK DUFRESNE: I would only add two more. The other piece that kind of intersects is the Medicaid waiver. As you know, is a major funding tool that's used in this country for services and supports for people in the community, and every five years or so that has to come up for renewal. And I have always felt that waivers are more than funding documents, that they really include policies and procedures, and I think that they need to dovetail with the regulations. And so I was asked as well to take a look at your waiver as it comes up for renewal. And then the final thing, Senator, was I also do a lot of training and consultation for both agencies, providers, and for state folks as requested, and I've been asked if there's an interest to provide some training and technical assistance just in general about trends and about information. But that's really... []

SENATOR LATHROP: And who would be the recipient of that training? []

DERRICK DUFRESNE: So far we've identified...I've been spending some time with the

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service coordinators... []

SENATOR LATHROP: Okay. []

DERRICK DUFRESNE: ...about that, and then we've just had some initial discussions with providers, particularly I'm going to be attending the...I've attended already two meetings of the statewide providers association and I'm meeting with the Omaha providers on May 28 to kind of explore... []

SENATOR LATHROP: Okay. []

DERRICK DUFRESNE: ...what kind of training needs there might be. []

SENATOR LATHROP: I want to give everyone here an opportunity to ask questions but I did want to have you kind of... []

DERRICK DUFRESNE: Thank you. []

SENATOR LATHROP: ...give us a little bit of background, tell us what... []

DERRICK DUFRESNE: I hope I answered the question. []

SENATOR LATHROP: Yeah. Yeah, you did... []

DERRICK DUFRESNE: Okay. Thank you. []

SENATOR LATHROP: ...and did a find job of it. []

DERRICK DUFRESNE: Thank you. []

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SENATOR LATHROP: Anybody here have questions at least? []

SENATOR GAY: I do. []

DERRICK DUFRESNE: Yes, sir. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: You had talked about those regulations when you're doing a review. You're seeing too many or just not written correctly for maybe where the...where other people have been going as far as delivering the services. Do we need to complete rewrite them, get rid of a bunch of them, or what's your plan there? []

DERRICK DUFRESNE: Senator Gay, that's a great question. I guess what I would say is that what I have seen across the country is regulations beget regulations, and that...this is not a real deep thought but I don't think that it really is regulations that keep people safe. I think it's people that keep people safe. Having said that, I certainly think that the primary function is really the Hippocratic oath of doing no harm and that anybody that accepts public money has to accept what I've been calling the sacred trust, and the sacred trust is this person is primary. If you accept the responsibility for this person, first and foremost, we must be able to guarantee the citizens of Nebraska and families that people are safe. And so I believe that there does need to be a role for health and safety, and there does need to be the opportunity for people to know that, frankly, they won't be worse off by coming to our care, just at a very minimum. And then, to build on that, to say that we will provide the care necessary and the support necessary for people to thrive in whatever setting that they're in. And so when I reviewed the regulations, without really knowing anything about the history and not really been given a whole bunch of information other than to review these, what I saw was not unusual, not bad, but some very prescriptive things that I think need to be in place for the ability certainly to protect health and safety, but tend to, in especially

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smaller integrated settings in particular, that tend to be at times, I guess I'll use the word, "overkill." But I haven't been asked yet to review the overall regulations. What I've been asked to do is, once I made the comment about the fact you've got 70 percent of the folks that are living in settings of three or less and that these are in the community, that they are in typical types of settings, why don't we look at trying to maybe draft a set of regulations that's been come to be known across the country as supported living? And so I would like to start with, rather than the whole elephant, to start with where you've got most of your folks living and then to look and see what parts of that need to be expanded. If you're asking me point blank whether or not I think the regulations need a fresh look, my answer would be yes. If you're asking me if the comments were on target, I would say yes. If you're asking me, as I met with Public Health, does there need to be a role for Public Health in the health and safety of individuals supported, I would say yes. But we're starting with one piece and that's the support of the... []

SENATOR GAY: Okay. Can I have one follow-up question? []

SENATOR LATHROP: Sure. []

SENATOR GAY: Okay. But I guess the point I'm getting to, so you're saying, well, we need to maybe get new regulations. What I'm saying, are the current regulations too much and are they hindering the ability of somebody to, what you said, just provide that service? That care is number one. Do we have excessive regulation that people are just looking to regulations and forgetting about the service? I'm not saying forgetting about the service. Are we regulating people to that's all they think about, not delivering services? []

DERRICK DUFRESNE: I understand, and I guess what I would say quite directly back to you is that after seven weeks I don't know that I'm capable of making that. But I will say that I have not seen in states the length or complexity of prescriptive regulations being a compatible statement with saying that people are safe. []

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SENATOR GAY: And again, not to (inaudible) but you're saying we're pretty excessive (inaudible). []

DERRICK DUFRESNE: I would say... []

SENATOR GAY: Okay. That's... []

DERRICK DUFRESNE: ...that your regulations are very prescriptive here. []

SENATOR GAY: All right. []

DERRICK DUFRESNE: And I would say the smaller the setting and the more it is not even setting specific in terms of some things, that I think that regulations can get in the way. Having said that, people need to be healthy and safe in wherever people are. Did I answer your question, Senator? []

SENATOR GAY: Yeah. Yeah. []

DERRICK DUFRESNE: Thank you. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: When you look at our community-based programs and our goal to moving as many people as we can from the Beatrice Center into community-based programs, have you had a chance to evaluate the community-based programs and do we have the appropriate kinds of services that are available? Because that's where my greatest fear lies. We're not going to move from Beatrice, place people into community-based programs, I'm not so sure they're going to go into a more...into a safer environment. I guess that's what I'd like to know, what your thoughts are. []

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DERRICK DUFRESNE: I think that's a great question. If it's okay, I'd like to answer it at two different levels. []

SENATOR HARMS: Okay. []

DERRICK DUFRESNE: And again, I would like you to please accept that I've been coming here now for seven weeks and that, while I've known actually a number of the providers here for a number of years, I do not have yet nor have I been asked in any part of my role to do a quote, unquote evaluation of community providers. I'll say two things. The first thing is that I don't know if people outside of this state would look at things differently than inside, but for those of you that are inside the state it appears to me, and this is observation, not fact, that you really have been afforded a perfect storm here that I see comes along not by necessarily plan or design. I don't know. I haven't really been privy to those discussions. I'm not involved in anything other than the piece that I've been asked to do. But I think that there's an opportunity here that is not going to last forever to try to maybe take a step back. And again I want to say the system that I knew back in the seventies that sprung out of ENCOR that has then gone to other community-based providers, that the reputation of some of the providers that I know here that do business in other states is very good. What I worry the most about are people that are the most vulnerable, are people that have intensive support needs. And I was a provider for 15 years myself, both in institution and community settings, and I can't imagine, Senator, that the providers here are any different than they are in the places that I've been and worked, and that is providers try to do what they're asked to do, with the resources that they're given, to the best of their ability. And I have not found that many providers that are able to quote, unquote retire to the Bahamas based on the money that they're paid. I think people want to do the right thing for people. And then I think it branches and the way I think it branches is...and I promise I will answer your question and be brief, but the part that it branches on is whether or not the state and the federal government and the funders provide user-friendly, supportive ways for people to

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go about their business that doesn't either strangle or inhibit their ability to do that. And sometimes regulations do that, sometimes insufficient funding does that, and sometimes micromanage does that piece. That's one piece. The second branch is the challenge to the providers and the challenge to providers is that we've been doing group homes in this country for close to 50 years. We've had institutions for 145 years. And if you're going to have somebody in the community, then that is a sacred trust and that requires the supports necessary, and if the state is willing and has the capacity to put the fiscal resources then there's that piece of it. But the people that I think deserve far greater attention that don't get it nationally, and I haven't been here long enough to know how it is here, are the people that do this at the direct support level and those direct support level have the most direct influence on quality, whether or not it's in an institution or community setting, and if there's any place we don't want to cut funding, if there's any place that we don't want to skimp, it's on training and support of those folks. Finally, I will say if the direct support work force is not supported and trained then this will probably over time, if it hasn't already, slide in the community because there's as many people or more in the community that have these needs as there are elsewhere, including your current waiting list. And so, yes, you have reason to be concerned and the question is whether or not there is the training and support necessary that's offered to people medically, clinically. And more importantly, on a day-to-day basis does somebody work with somebody that cares about them? Do they have somebody that knows what their needs are? So, yes, I think you have reason to be worried, but I also think you have reason to rejoice in the fact that there are a number of people that I think are being well supported here already. []

SENATOR HARMS: Well, when you look at the number of people that are on our waiting list and the fact we are taking that issue on, I worry a little bit about whether or not we have the proper facilities to take on that waiting list and place people in group homes. And then coupled with the fact that what we heard through so many people who testified before us for, what, the last six or seven months, there's a shortage in doctors, psychologists, psychiatrists, social workers, you know, the tech side, and it's...the

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further you would go into rural America the more complex the issues become and it just...that's what I'm concerned about. There's more than just what you're talking about. There's that other side that I have some worries about. []

DERRICK DUFRESNE: Let me answer that real briefly. I say this to the committee not as either a badge of courage or anything that gives me extra credibility but I also come here as the sibling of a person with developmental disabilities, and my brother turned 72 on March 28. When my parents had my brother in 1937, they were faced with a very difficult decision about whether or not to place him when the doctor basically said that they should place him and get on with their lives. And I will never judge any parent that makes any decision. My parents made the decision to bring my brother home. And my mother was very ill during a good portion of her life and a year before she died they were able to find a residence for my brother. I feel, I pain for, I hurt for the families that are on the waiting lists because of the very thing that you've said, and the current system is unsustainable. It is absolutely...whatever you do about anything else, the current system is unsustainable. And what I have been trying to say for my piece of this is I don't use the word "facilities" for what I do because I find so far in Nebraska that there's an abundance of housing. The question is whether or not that housing is accessible. And so I think the question is these parents...people have asked me a lot, where did you learn that people with significant needs can live in the community, where did you learn that people who have significant medical supports with shunts, J-tubes, G-tubes, require turning, positioning, where did you learn and where do you get off in saying all these people can live in the community? And my response is parents, because these parents have been providing this support. And I'll just finish with one piece of fact that I think would be of concern, is that right now nationally we have about 450,000 people in all 50 states living in community residences in any type, and right now there's 750,000 people living in settings at home with families whose caregivers are over 60. We have another 500,000 that are living with caregivers that are between the ages of 30 and 60, and there's a perfect storm on the horizon that's going to come crashing down if we don't rethink this whole thing. So we need to rethink, as far as I'm

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concerned, everything except people deserve to be safe and deserve to be loved wherever they are, and I think that there's some ways that we can gain efficiencies, at the same time not lose some of that, and I'm happy whatever part of it I'm part of to help with that. []

SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thank you, Doctor. In regards... []

DERRICK DUFRESNE: Oh, I'm not a doctor. I don't play one on TV. Thank you very much. (Laugh) []

SENATOR WALLMAN: Oh, okay. In regards to disability assessments or review, do you think we're unrealistic to get improvement, you know, in ICF/MRs? Is the government unrealistic, is CMS unrealistic? You know, we get state, federal funds. Do you think we're unrealistic? []

DERRICK DUFRESNE: Can you tell me what you mean by unrealistic, Senator? []

SENATOR WALLMAN: Do you think we're unrealistic to, you know, to improve in conditions or your mental capabilities, you know, when you are in an ICF/MR. []

DERRICK DUFRESNE: Senator, what I would say, if I understand your question, is that in my own family my parents were told that my brother wasn't going to live beyond age seven, and if he lived to be age seven he would never be able to care for himself or would never be able to in any way really improve and he had the mind of a seven-year-old. My brother wouldn't necessarily remember any of your names but he remembers what happened in 1953. He knows stuff that I don't know. We don't know, because there's no way to test it, to what degree people grow. What we know is their performance, and there's a difference between growth and performance. So the

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purpose of public funding in my mind, whether it's state or federal, should be that it should be an investment rather than an expense. And the question is, what are the taxpayers and what are the families and what is the person getting in exchange for the investment? And I think that the federal and state government, I mean I will tell you that what is happening here, I wish I could tell you it's unique, but I spend a lot of my time in states that are going through exactly the same thing, Senator. And the things that Senator Harms talked about in terms of finding the resources, there is a national issue about finding resources, especially clinical resources, particularly in more rural areas of this country. This is not a Nebraska issue. But the federal government, you know, many people think that Medicaid is a federal program that gets state funding. It's exactly the opposite. It's a state program that gets federal funding. And so they're willing to put in unlimited resources at the federal level as long as you're willing to match them. The question is, how are you matching them and to what degree and for what purpose, so it's the outcomes. But, yes, I absolutely believe that it can be an investment wherever people live, sir. []

SENATOR WALLMAN: Thank you. I do too. []

DERRICK DUFRESNE: You're very welcome. Thank you. []

SENATOR LATHROP: I want to ask a few questions and I'm going to, just so that we don't run out of time, see if we can shorten up what we...how we get to the point you want to make, and not to cut you off, but... []

DERRICK DUFRESNE: Yeah. Oh, no, this...I'm... []

SENATOR LATHROP: ...I'm hearing you say a lot of different things and, because you've given me a lot of material, I'd like to ask you a few questions. []

DERRICK DUFRESNE: Have at it. []

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SENATOR LATHROP: Do I hear you say, in talking about whether we're making an investment versus paying an expense, and that we have a system that's not sustainable, and what people deserve is to be safe and loved, do I hear in there somewhere that you think right now the current system, which involves active treatment and habilitation, that that's not where we should go; that we should be focusing on safe and loving environments and that the habilitation is something that makes this process unsustainable? []

DERRICK DUFRESNE: No, sir, and I'm sorry if I said that. []

SENATOR LATHROP: You didn't say it. I just wanted to make sure you didn't imply it. []

DERRICK DUFRESNE: I think people deserve real lives and I think, what I would summarize it, if I were a king and could wave a magic wand and say what we should evaluate, it'd be five simple things, and this will be real short: live, work, love, play, worship. We should be evaluating do people have a life, are they living at a place they want to live with people they want to live with; do they have some sort of income; do they have the opportunity when they're not working, when they're not involved in activities, to literally just play; do they have people who care about them and love them; and if they want to worship, do they have the ability to express their faith? I think those are habilitative in nature and I think those are important. []

SENATOR LATHROP: Okay. You make a point about the fact that many of our folks are living in...70 percent of them are living in... []

DERRICK DUFRESNE: Yes. []

SENATOR LATHROP: ...in settings with three or fewer people in those settings. Is that because you think that's where we ought to be going that you bring that up? []

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DERRICK DUFRESNE: Here's what I would say. Since 1981, when President Reagan signed into law the home- and community-based waivers, they have constantly and consistently been voluntary. It is not a statutory right or a statutory authority; it's an option. In about...don't...please don't hold me exactly to this, but in about 2002, something like that, the number of people on waivers nationally surpassed the number of people in ICFs. And one of the requirements in the waiver is that people have a choice of provider and a choice of institutional, community-based services. I personally am absolutely willing to let the market drive that, but the market, when people have a choice, tend to be that people choose to live with a fewer number of people rather than more people. And, in general, people tend to choose things that look like where you and I live, where we work, where we play. So that's where most people already live so, yes, I believe that that is...and, by the way, it is a federal policy. CMS has actually adopted this as a federal policy. []

SENATOR LATHROP: I want to follow up on a question that Senator Harms asked you because I'm not sure I caught the answer, and that is your job, among other things, with the state, you've been doing this for seven...coming to Nebraska for seven weeks. []

DERRICK DUFRESNE: Yes, sir. []

SENATOR LATHROP: And your role, at least in part, is to place these folks that have been moved to hospitals from BSDC. Have you been responsible for placing any of those folks? []

DERRICK DUFRESNE: No. And actually, my job is not placement. My job is really consultation. []

SENATOR LATHROP: Consultation with those responsible for placing. []

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DERRICK DUFRESNE: Yes, sir. []

SENATOR LATHROP: Has your consultation with those responsible for placement led to the placement of any individuals? []

DERRICK DUFRESNE: Not yet. []

SENATOR LATHROP: Okay. The other question that Senator Harms asked and it was a pretty straightforward question and I'm not sure I got the answer. []

DERRICK DUFRESNE: Okay. []

SENATOR LATHROP: And this is the question as I heard it, and that is, if we are looking as a state at trying to transition people from these hospital settings or BSDC, for that matter, into the community, do we have the capacity to do that? You've been at it seven weeks. Your job is to find community placements for these people. As a consultant, you have to have looked at our community-based programs. Is that capacity there for these folks? []

DERRICK DUFRESNE: I would say for... []

SENATOR LATHROP: Do we have the services in the community setting? []

DERRICK DUFRESNE: I'm sorry, I didn't mean to interrupt. If you're asking me my impression after seven weeks, the answer is for a vast majority, yes. []

SENATOR LATHROP: A vast majority of the 20 that are left? []

DERRICK DUFRESNE: Yes. []

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SENATOR LATHROP: Okay, so we at least have... []

DERRICK DUFRESNE: Oh, actually... []

SENATOR LATHROP: ...we at least have 18 spots in the community setting? I mean we're...here's our problem. We don't, as a Legislature, we don't run Health and Human Services. []

DERRICK DUFRESNE: Got it. []

SENATOR LATHROP: We have people that serve on the committee and so we don't run that branch of government. []

DERRICK DUFRESNE: Understand, sir. []

SENATOR LATHROP: Our job is to get some sense of whether or not it's being done well, to the extent that's our focus. Our question and the thing that we grapple with in this committee is, okay, everybody comes in here one after another and says the best thing for people is to be in the community. We don't have a sense of whether the community is ready for these people. Senator Harms was good enough to try to find and come up with \$15 million to help move people off the waiting list and, honestly, as we sit here today, we don't know if the community is ready for them. Do you have any sense of that? []

DERRICK DUFRESNE: Yes. []

SENATOR LATHROP: And what's your sense? []

DERRICK DUFRESNE: My sense is that long before I ever got a chance to grace your wonderful state, long before the trials and travails of the last year, that going way back

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for 30 to 35 years that providers in this state have provided support to people across this state, including some people with some pretty significant disabilities. The fact that of the 47 people that at least a goodly number of them have already gone to providers I think bespeaks well for that. I will tell you that I think that there is the need for some additional approaches and very simply would say this. The approach that I bring is not to find the slot or not to find the facility and place the person, but to find the person and then find the place. When you do that, it changes the equation. But, yes, I will tell you I think the state has both great capacity, has already demonstrated it, and families have already been providing these services at home and what we need to do is to try to both support their efforts as well as to find something that's as closely related to where they are right now as possible. []

SENATOR LATHROP: I'm trying to figure out if you are bringing to the state a philosophy of take these people back to their family and give them the supports that the state can offer. Do I hear that implied in your answers? []

DERRICK DUFRESNE: I will tell you one of the things, if I ever seem obtuse, I am not an obtuse person. I will tell you this. I've been engaged to ask for people in the hospitals, for whom there is not yet an identified provider and for whom the family is supportive of looking at options, to see whether or not there is an option to have folks live in the community, and I think we are being successful in the transition process but nobody has yet moved with some of those folks. If you're asking me for the people on the waiting list if they are currently at home, does the family desire the person to live at home and get supports at home or does the family desire a residence outside the home, if the family desires a residence outside the home what I would say we should do is rather than build something as the first choice to look and see if the person wanted to live close to them and then what supports are needed. I think there's providers that are doing that now and other providers that can do that. []

SENATOR LATHROP: My question was whether or not you're bringing a philosophy

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that involves encouraging people to move back with their families and then providing them services. []

DERRICK DUFRESNE: No. My philosophy is that if I am asked and the family and the system is interested in supporting people in the community, then where does the person in the family wish for the person to live? If the person and the family wished to live at home, then I think we should use those dollars to support people in natural family settings. If the person and the family desire community, then I think we should be looking for community alternatives that are small and integrated that follow those five principles that I talked about. []

SENATOR LATHROP: Okay. Senator Cornett has a question for you. []

SENATOR CORNETT: You stated that you've been coming to the state for seven weeks now? []

DERRICK DUFRESNE: Yes. []

SENATOR CORNETT: And that it's your job to help the people that are looking to place the people that are in the hospital, to give them advice, consultation on how to do that or what the appropriate setting would be, correct? []

DERRICK DUFRESNE: Yes, Senator. []

SENATOR CORNETT: In that seven weeks, no one has been placed, correct? []

DERRICK DUFRESNE: Correct. []

SENATOR CORNETT: Why? []

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DERRICK DUFRESNE: A great question. I think for a couple of reasons. Very directly, I would say that the movement of people to the hospitals was decided upon, I really don't even want to comment on that except to say it was decided upon, and there was the need to stabilize medically the individuals in that setting, to deal with the supports that are needed in the hospital setting, and then to transition people. And because people are not chess pieces that one moves on the board, given how quickly people moved to the hospital, any movement needs to be done with both planning, with supports, and to make sure that in the community side that the supports are in place so that the individual doesn't fail. So part of the time has been spent talking with providers, talking with medical staff. I go to Bryan every week and meet with the staff there, just had a meeting this morning with the medical staff, and part of it is making sure that the providers are ready, willing and able to find the right person for this person to live with or to provide support to. So I think that's worth making sure it's done right. And I think it may seem like a switch was on that these people were starting to consider community placement when I got here and why isn't anybody moved. People are actively in the process with providers, where approved by the guardian, and in some cases we have only recently gotten approval from the guardian to pursue this. Then there's the lag time, once the guardian says okay, to set up the setting, hire the staff, do the training of the staff, make sure that the setting is safe, making sure that the attendant regulations are met, and making sure that the person moves to a setting that does not jeopardize the very health that they were moved in the first place to attain. []

SENATOR CORNETT: A couple more questions. []

DERRICK DUFRESNE: Sure. []

SENATOR CORNETT: When you first started testifying and how you ended up helping out the state of Nebraska, you said you thrived on chaos. []

DERRICK DUFRESNE: Yes. []

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SENATOR CORNETT: I'm assuming you see that we are in a state of chaos in regards to our developmental disabilities for the people that have been moved, are in the hospitals, or do you mean to the system as a whole? []

DERRICK DUFRESNE: I meant the system as a whole, and I'm sorry if that seemed like a flip comment. What I guess I was saying... []

SENATOR CORNETT: No, it was not flip, but it actually was very telling. []

DERRICK DUFRESNE: ...what I was saying is that I don't tend to get called into states, including my own where I live in Missouri, when things are going well and for people for whom there is either easy placement or for people that don't have very challenging supportive needs. And the issue we're up against now is that numbers of people have either been placed, I hate this term, Senator, but are either easy to place or require little supports and the people that we now are looking to provide supports to in many cases have more complex needs. []

SENATOR CORNETT: And therefore are harder to place and I under... []

DERRICK DUFRESNE: Yes. Yes, Senator. And not only that, but it requires a special approach by a provider. It requires a family to be, I don't know what the word is, Senator, comfortable with, supportive of the fact, if their loved one is going to live here that these supports are going to be in place. And so, yes, I think that it's a different environment. []

SENATOR CORNETT: To follow up on that, you said that you believe that we have the community-based services in place to provide services for both the people that are in the hospital, the people that are...want to move from Beatrice, and for people on the waiting list. And this is kind of a two-part question. I'm sure you've seen how extensive

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our waiting list is and most states do not have that type of a waiting list. You're from outside of Nebraska and yet I hear on a daily basis from our providers, our community-based providers, that they do not have the capabilities now of addressing the waiting list. Do you feel that we do have the services in place? Do you feel that they will...how long do you feel that it would take them to get to the point where they could, we could logically address the waiting list? []

DERRICK DUFRESNE: Okay. Is it okay if I ask you a question back? []

SENATOR CORNETT: Yeah. []

DERRICK DUFRESNE: Where did you hear that...when you talked about the waiting list, that this is not necessarily the case elsewhere? []

SENATOR CORNETT: We've heard it time and time again in hearings that the extent of our waiting list is greater than other states. []

DERRICK DUFRESNE: Okay. I can just tell you, as somebody that travels, the reason that I felt...I don't want to say comfortable or happy... []

SENATOR CORNETT: Uh-huh. []

DERRICK DUFRESNE: ...with the challenge you've got, is that this is a national problem just for the reason you just gave. []

SENATOR CORNETT: The waiting list? []

DERRICK DUFRESNE: The waiting list. We're facing an absolutely perfect storm nationally in the next three to seven years. []

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SENATOR CORNETT: When you say that and you talk about people that are at home with their parents, are they people that have been...that we just know are going to have to move to community-based because of the age of their parents or are these actually families that have placed their loved ones on a list, looking? []

DERRICK DUFRESNE: Great question. []

SENATOR CORNETT: There's a difference. []

DERRICK DUFRESNE: Yeah, I absolutely agree with you. And I think the people that have been placed on the list... []

SENATOR CORNETT: I mean do other states actually have lists of people that are waiting for services or are we just assuming that these people are going to need services in the future? []

DERRICK DUFRESNE: In my state of Missouri, since we never do anything simply, we have a level 12 system. []

SENATOR CORNETT: Okay. []

DERRICK DUFRESNE: And we have about 5,000 people. []

SENATOR CORNETT: That have requested services. []

DERRICK DUFRESNE: Yes. []

SENATOR CORNETT: Okay. Second part of the question... []

DERRICK DUFRESNE: So we have...and in almost every state I go to there is both the

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informal waiting list, Illinois doesn't recognize a waiting list but they've just come up with something that's called the PUNS that is essentially a waiting list, and already within I'd say 11 months... []

SENATOR CORNETT: I was going to say I know Illinois didn't have one. []

DERRICK DUFRESNE: ...the list is just overwhelming. So there is absolutely a need for those services. I think I know where you're headed with this and I don't think what I'm saying is incompatible. The question is, when you talk about capacity, are there providers in this state that are providing quality services to people of a bunch, a variety of disabilities? The answer is yes. Is there the capacity of every single provider to take new people into their system right now? The answer is no. I don't think that those are incompatible. The question is, is the provider unwilling to serve more people because of regulations, unwilling to serve more people because of lack of staffing, unwilling to serve more people for, you know, they've decided not to grow? And what I've heard from even in the time I've been here with providers is that it is not the unwillingness to serve more people. It isn't that they don't want to keep doing what they're doing. So the interest, the capacity of wanting to serve is there. What I have heard is the same thing I hear, frankly, in every state I go into--overburdened regulations, inconsistent application of regulations, lack of funding, lack of ability to find qualified staff, and then the attendant training issues to make sure the staff you have are able to provide the supports they need. []

SENATOR CORNETT: So while you're saying we have the capability of expanding our community-based services, we are not at this point in time capable of addressing the waiting list. They would have to expand their services and, based on the points that you mentioned, that would be difficult to do. []

DERRICK DUFRESNE: I do not want to speak for the providers of this state except what conversations that I've had so far. But if you're talking about...did you say 1,400,

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Senator? []

SENATOR CORNETT: Did I say... []

DERRICK DUFRESNE: Fourteen hundred people are...is that the number? []

SENATOR CORNETT: I...it's over 2,000. []

DERRICK DUFRESNE: Oh, I'm sorry. []

SENATOR CORNETT: It's over 2,000. I don't know the exact amount. []

DERRICK DUFRESNE: Over 2,000. I honestly don't know that piece of the answer except what I have heard, that it's not the unwillingness to support people. It's the other... []

SENATOR CORNETT: And we're not talking about the unwillingness. We're talking about the actual capability of supporting them. []

DERRICK DUFRESNE: And I'm saying to you, based on the conversations that I've had, that if you have user-friendly regulations that guarantee health and safety but do not overregulate and are not overly prescriptive, if you offer a flexible funding system that is based on the intensity of support of the individual, if you put money into the budget that allows for training of the staff that are most closely related to the person, and if you provide training and technical assistance that assists in the acquisition and maintaining of those quality staff, I believe that there is the capacity to expand to meet the needs on the waiting list. If you're asking me the way things are right now, based on the little bit of knowledge that I've gained in the seven weeks I've been here, I would say that you're going to continue to struggle. []

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SENATOR CORNETT: Thank you. []

DERRICK DUFRESNE: Did I answer your question? []

SENATOR CORNETT: You did. Thank you. []

SENATOR LATHROP: Yeah. Obviously we have trouble with capacity because we got ten people that went from the hospitals into nursing homes instead of into community-based settings, right? And if we had the right places for them to go, they wouldn't be going to nursing homes instead of a proper setting. And you would have to agree that nursing homes is a poor substitute for a developmentally disabled individual versus a proper community placement. Would you agree with that? []

DERRICK DUFRESNE: Yes, I would absolutely agree with that. []

SENATOR LATHROP: Okay. Let me ask one more question since we have to be on the floor at 1:30 and my last question at least for you is, you said you were here to be involved in the regulations. You've given us an outline of what they ought to look like. When will they be done? []

DERRICK DUFRESNE: I'm in the final stages, Senator, of making my recommendations on the portion--and I want to be clear when you ask me about quote, unquote regulations that the universe is this big--the draft recommendations on the piece that I call supported living are in my final draft and the... []

SENATOR LATHROP: Is that going to cover all the regulations we need or are you just taking care of one little slice of the regulation pie? []

DERRICK DUFRESNE: It depends on what I'm asked to do. I believe that they can take care of all of it and I believe it can be done. I'm not speaking for the department in giving

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you a date other than to say I think it would be done probably three months. []

SENATOR LATHROP: Okay. Does that cause anybody any additional questions, thoughts? Okay. We do appreciate you coming down here. []

DERRICK DUFRESNE: Thank you very much for inviting me. []

SENATOR LATHROP: We have to get upstairs because our afternoon starts in five minutes. []

DERRICK DUFRESNE: Thank you so much for your invitation. Thank you. []